



# Rhode Island Children with Special Health Care Needs

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FINDINGS FROM THE 2001 NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS

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MAKE HE<sup>♥</sup>ALTH PART OF YOUR FAMILY

RHODE ISLAND DEPARTMENT OF HEALTH

We need to build comprehensive  
medical homes for 35,000 children with  
significant special health care needs.



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The U.S. Maternal and Child Health Care Bureau defines children with special health care needs as “those children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health care-related services of a type or amount beyond that required by children generally.”

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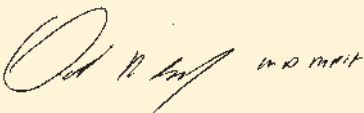
The Department of Health works to be sure all Rhode Islanders can live safe and healthy lives. Our Division of Family Health focuses on the health and development of Rhode Island's children and families. Over many years, we have helped build a family-centered community system of resources and services that can recognize and respond to children's needs in their homes, in medical practice, in child care, schools, and other settings. Good information on children's and families' health is a cornerstone of our mission. Therefore, this report on the Rhode Island results of the 2001 National Survey of Children With Special Health Care Needs is an especially important resource.

Our Office of Families Raising Children with Special Health Care Needs is responsible, under Title V of the Social Security Act, for assessing and addressing the health of children with special health care needs (CSHCN). Specifically, the Office is mandated to provide and promote family-centered, coordinated care for these children and to facilitate the development of community-based systems of service for them and their families. These values are key to ensuring medical homes for Rhode Island's most at-risk children, youth, and their families.

These rich survey data will help focus our work and investments on the issues Rhode Island parents or guardians report as most important for them to succeed in raising kids with (often complex) challenges. Among the strongest priorities from the survey are:

- » The overall prevalence of children with special health care needs in our state showing that we need to build comprehensive medical homes for 35,000 children with significant special health care needs.
- » The demographics, source of care, care coordination, and insurance status of these children in our state. Many of these children and families come from backgrounds that are very different than our mainstream medical system.
- » The impacts on the family of caring for a child with special health care needs. These families experience additional financial and employment stresses.

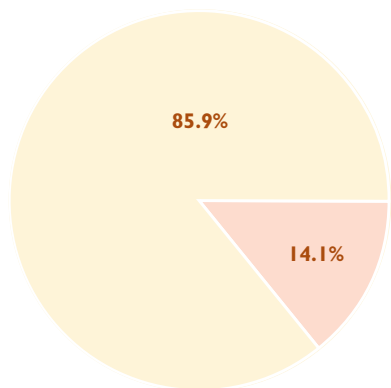
We hope this information will raise awareness of the need for medical homes for all children with special health care needs and lead to policy changes to ensure they receive the care they need. Please join us in this endeavor to move these data to action.



David R. Gifford, MD, MPH

Director, Rhode Island Department of Health

# Prevalence of Children with Special Health Care Needs



## PREVALENCE OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS IN RHODE ISLAND

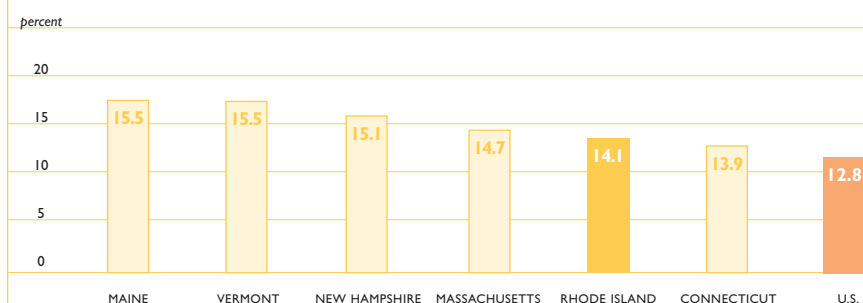
CHILDREN WITHOUT SPECIAL HEALTH CARE NEEDS **85.9%**  
N=214,599

CHILDREN WITH SPECIAL HEALTH CARE NEEDS **14.1%**  
N=35,265

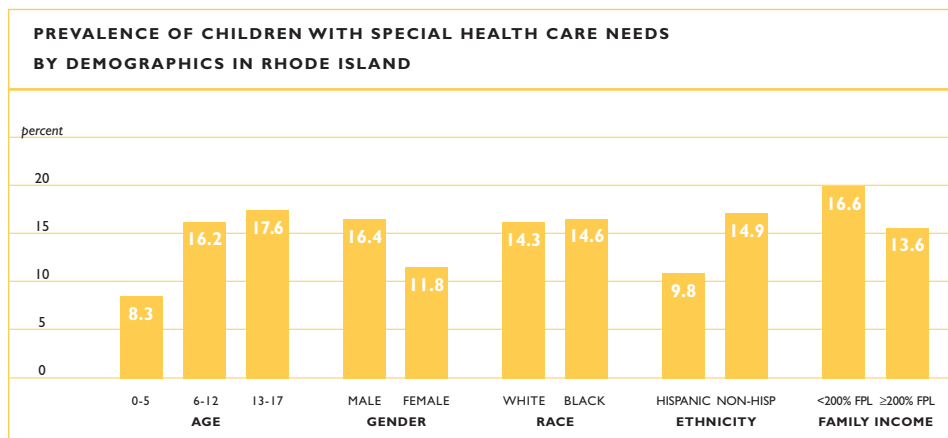
Rhode Island has the 5th highest rate of children with special health care needs among the 6 New England states, and the 16th highest rate among the 50 states and Washington, D.C.

- » 14.1% of non-institutionalized Rhode Island children under 18 years old have special health care needs, or an estimated 35,265 children, among the total child population of 249,864.
- » All New England states, including Rhode Island, have higher prevalence rates of children with special health care needs than the national rate of 12.8%.

## PREVALENCE OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS, NEW ENGLAND STATES AND U.S.



Rhode Island teenagers, males, non-Hispanics, and children living in low-income families have higher rates of special health care needs. There was no difference among White and Black children.

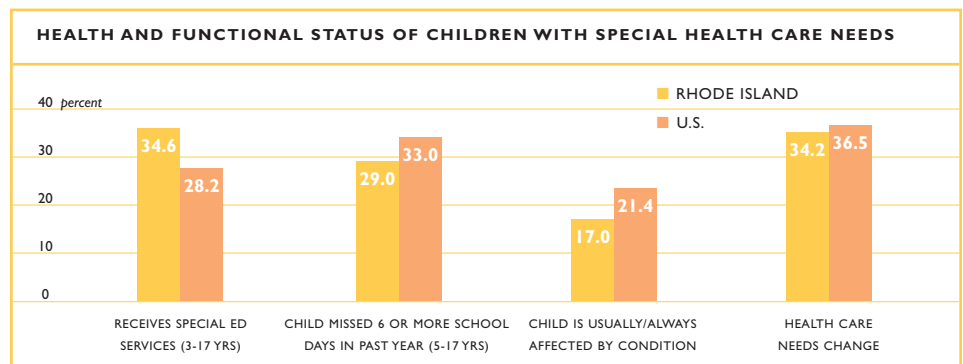


- » **Age:** Teenagers (ages 13-17) had the highest rate of special health care needs (17.6%) followed by children aged 6-12 (16.2%). The youngest age group (birth-5) had the lowest rate of special health care needs (8.3%) in Rhode Island. This may be because conditions have not yet been diagnosed.
- » **Gender:** Special health care needs are more common among boys (16.4%) than among girls (11.8%).
- » **Ethnicity:** Special health care needs are less common among Hispanic children (9.8%) than non-Hispanic children (14.9%).
- » **Family Income:** Children living in families with incomes below 200% federal poverty level (FPL) had a higher rate of special health care needs (16.6%) than children living in families with incomes at or above 200% FPL (13.6%).

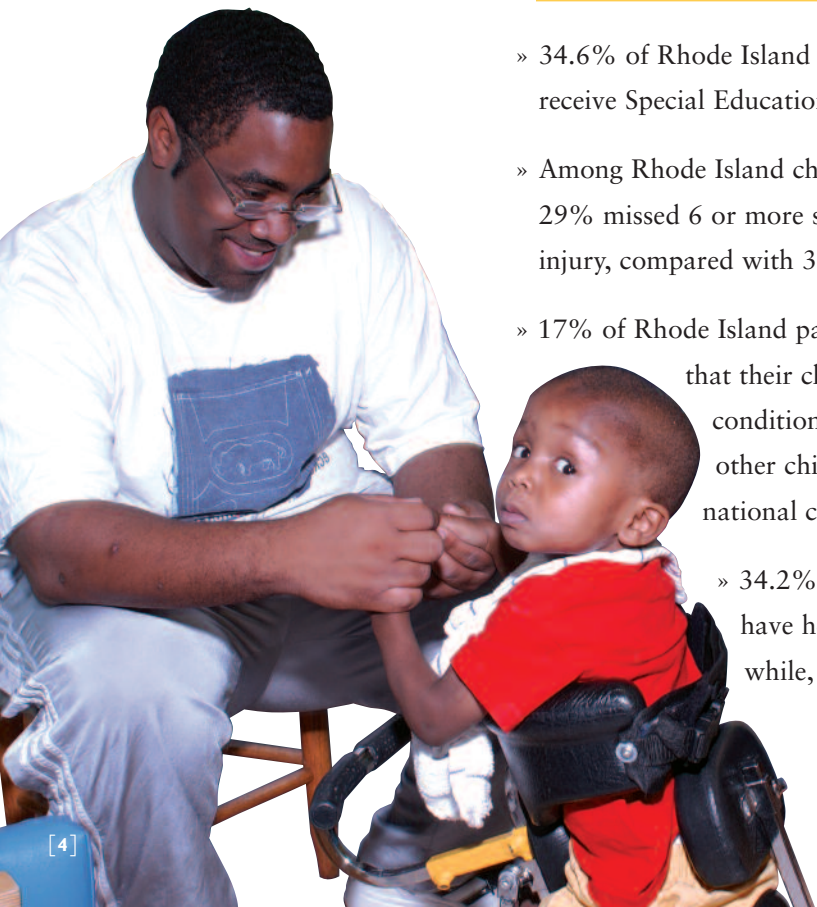


# Health and Functional Status

Rhode Island children with special health care needs have better health and functional status than their national counterparts, and are also more likely to receive Special Educational Services (special school, class, or tutoring).



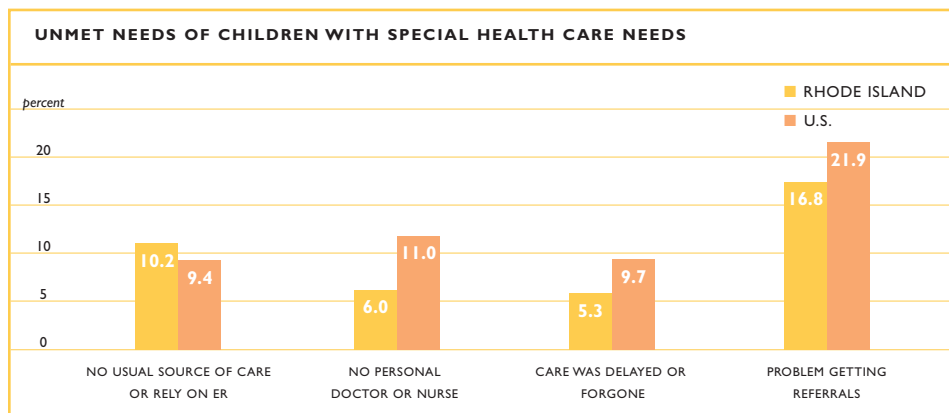
- » 34.6% of Rhode Island children with special health care needs ages 3-17 years receive Special Educational Services, compared to 28.2% of children nationally.
- » Among Rhode Island children with special health care needs ages 5-17 years, 29% missed 6 or more school days during the past 12 months due to illness or injury, compared with 33% of children nationally.
- » 17% of Rhode Island parents of children with special health care needs reported that their child's medical, behavioral, emotional, or other health conditions usually or always affected their ability to do things other children their age do, compared with 21.4% of their national counterparts.
- » 34.2% of Rhode Island children with special health care needs have health care needs that change all the time or once in a while, compared with 36.5% of their national counterparts.



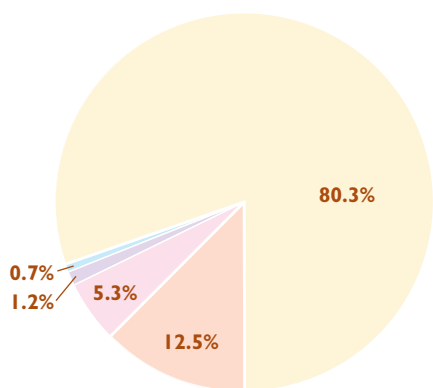
# Access to Care

**In Rhode Island, children with special health care needs are more likely to have a personal doctor or nurse and to get medical care. However, 10% still have no usual source of care or they go to the emergency room.**

- » 10.2% of Rhode Island parents of children with special health care needs have NO usual place to go when their child is sick, or they rely on the hospital emergency room. This compares to 9.4% of US parents of children with special health care needs.
- » 6% of Rhode Island children with special health care needs have NO personal doctor or nurse, compared to 11% of their US counterparts.
- » 5.3% of Rhode Island parents of children with special health care needs had a time when they delayed or went without health care for their child during the past 12 months, compared to 9.7% of US parents. (Health care means services such as, medical care; dental care; mental health services; physical, occupational, or speech therapies; and special education services.)
- » Among those who needed a referral for care from a specialist, 16.8% of Rhode Island parents of children with special health care had a problem getting a referral to a specialist during the past 12 months. This compares to 21.9% nationally.







**SOURCE OF USUAL CARE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS IN RHODE ISLAND**

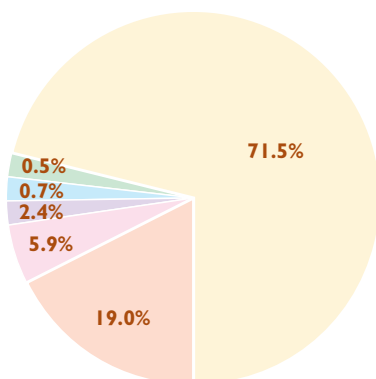
DOCTOR'S OFFICE	80.3%
CLINIC OR HEALTH CENTER	12.5%
HOSPITAL OUTPATIENT DEPARTMENT	5.3%
HOSPITAL EMERGENCY ROOM	1.2%
OTHER	0.7%

Of those Rhode Island children with special health care needs who have a usual place to go when they need care, the majority go to a doctor's office for their routine health care.

- » Of those Rhode Island parents who have a usual place to go for their child's health care, 80.3% go to a doctor's office, with the rest going to a health center or clinic, a hospital outpatient department, emergency room, or some other place.

Children with special health care needs in Rhode Island are more likely than their national counterparts to have a personal doctor or nurse and to have a pediatrician as a personal care provider.

- » 94% of Rhode Island children with special health care needs have a personal doctor or nurse, compared to 89% of their national counterparts. A personal doctor or nurse is the health care provider who knows the child's health best.
- » Of those Rhode Island children who have a personal doctor or nurse, 71.5% have a pediatrician (60.2% in US); 19% have a general practitioner (29.6% in US); 5.9% have a specialist (5.5% in US); 2.4% have a nurse practitioner (2.7% in US); and 0.7% have a physician assistant (1.7% in US).



**TYPE OF PERSONAL CARE PROVIDER FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS IN RHODE ISLAND**

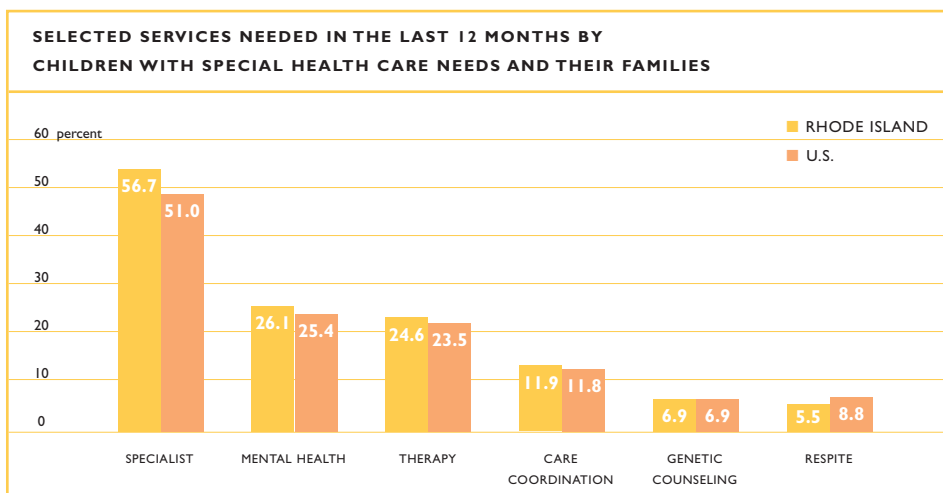
PEDIATRICIAN	71.5%
GENERAL DOCTOR	19.0%
OTHER SPECIALIST	5.9%
NURSE PRACTITIONER	2.4%
PHYSICIAN ASSISTANT	0.7%
OTHER	0.5%





**Rhode Island children with special health care needs and their families needed slightly more medical services than their national counterparts except in the areas of genetic counseling and respite care.**

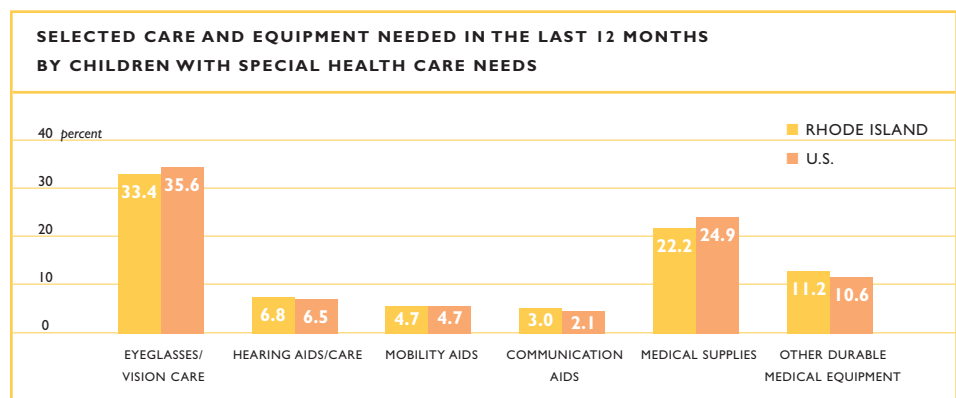
- » 56.7% of Rhode Island children with special health care needs required care from a specialty doctor, compared to 51% of their national counterparts.
- » 26.1% of Rhode Island children with special health care needs required mental health care or counseling, compared to 25.4% of their national counterparts.
- » 24.6% of Rhode Island children with special health care needs required physical, occupational, or speech therapy, compared to 23.5% in the US.
- » 11.9% of Rhode Island parents of children with special health care needs needed professional care coordination among the child's different health care providers and services. This compared to 11.8% of parents in the US.
- » 6.9% of both Rhode Island and US parents of children with special health care needs needed genetic counseling for advice about inherited conditions related to their child's medical, behavioral, or other health conditions.
- » 5.5% of Rhode Island parents of children with special health care needs needed respite care (having someone to care for the child so that family members could do other things), compared to 8.8% of parents in the US.



## Rhode Island and US children with special health care needs required similar specialized medical care and equipment.

In Rhode Island, children with special health care needs required:

- » eyeglasses or vision care during the past 12 months (33.4% compared to 35.6% in the US).
- » hearing aids or hearing care (6.8% compared to 6.5% for the US).
- » mobility aids or devices, such as canes, crutches, wheelchairs, or scooters (4.7% in both Rhode Island and the US among children ages 3-17 years).
- » communication aids or devices, such as communication boards (3% compared to 2.1% in the US).
- » disposable medical supplies (22.2% compared to 24.9% in the US).
- » durable medical equipment that is not disposable (11.2% compared to 10.6% in the US).



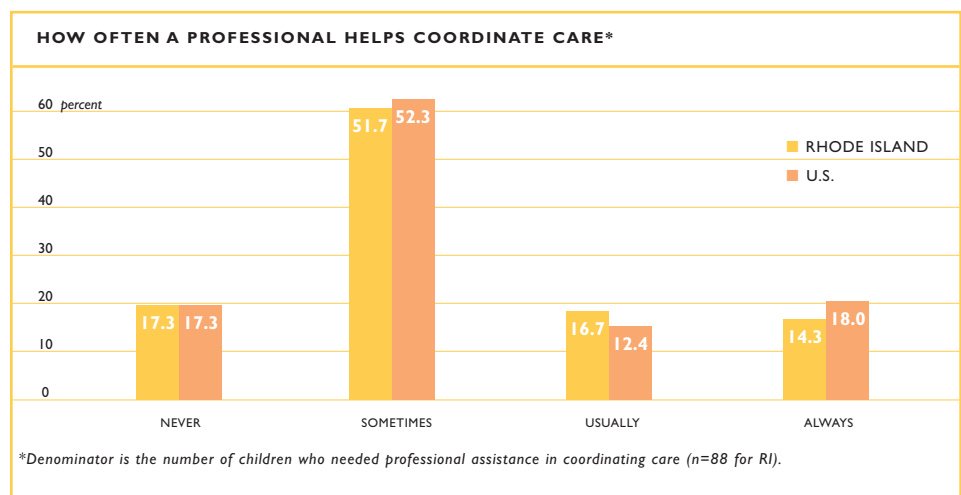
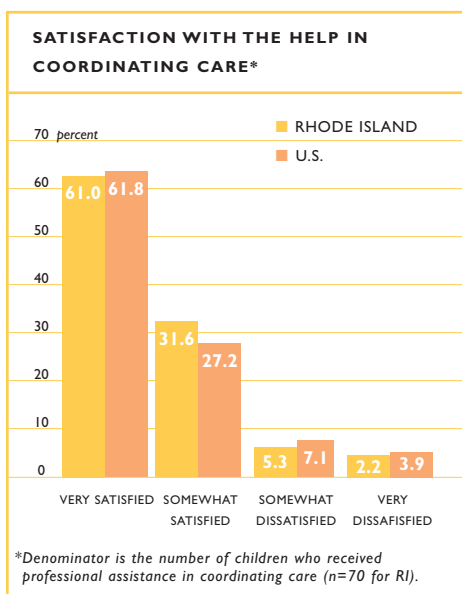


90% of Rhode Island families of children with special health care needs report that doctors make them feel like a partner in their child's care.

# Care Coordination

More than one in six Rhode Island parents of children with special health care needs reported that professionals never help them coordinate care\* for their child. One in thirteen Rhode Island parents of children with special health care needs were dissatisfied with the care coordination they received.

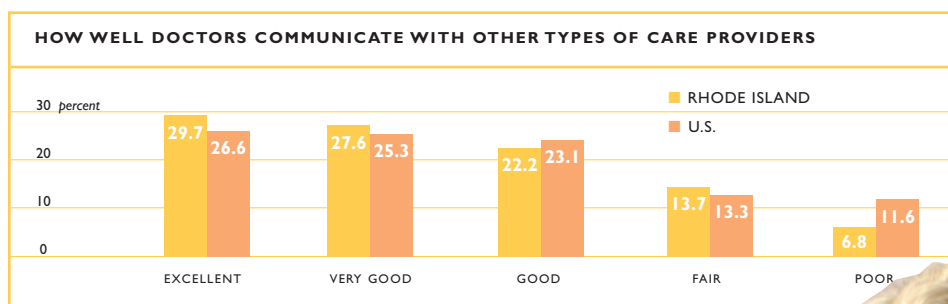
- » Of those who needed professional care coordination for their child, 14.3% of Rhode Island parents reported that professionals always helped them coordinate their child's care, compared to 18% nationally.
- » Of those who needed professional care coordination for their child, 17.3% of parents in both Rhode Island and the US expressed that professionals never help them coordinate their child's care.
- » Of those who received care coordination from professionals, 7.5% of Rhode Island parents reported that they were very dissatisfied or somewhat dissatisfied with the help they had received in coordinating their child's care. This compares to 11% of parents in the US.



\*Coordinating care includes making sure that the child gets all the services needed and ensuring that these services fit together in a way that works for the child. It also includes making appointments and making sure providers are sharing information.



Health care providers for children with special health care needs in Rhode Island tend to communicate better with the child's other types of care providers, such as school, the Early Intervention program<sup>1</sup>, child care providers, or vocational rehabilitation program<sup>2</sup>, than health care providers in the US. However, one in five Rhode Island parents of children with special health care needs rated their child's health care providers as poor or fair in communicating with other types of care providers.



» 57.3% of Rhode Island parents of children with special health care needs rated their child's doctors and other health care providers as excellent or very good in communicating with the child's other care providers, compared with 51.9% of parents in the US.

» One in five (20.5%) Rhode Island parents of children with special health care needs rated their child's doctors and other health care providers as poor or fair in communicating with the child's other care providers, compared with one in four (24.9%) parents in the US.

*1 Early Intervention services are defined as: family training, counseling, and home visits; health services; medicine; nursing; nutrition; occupational therapy; physical therapy; psychological services; coordination services; social work services; special instruction; speech-language therapy; transportation, communication, or mobility devices; and vision and hearing services.*

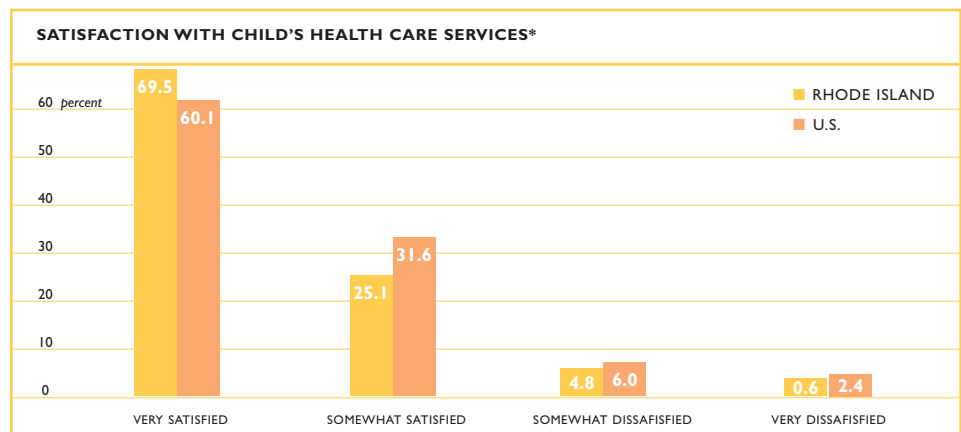
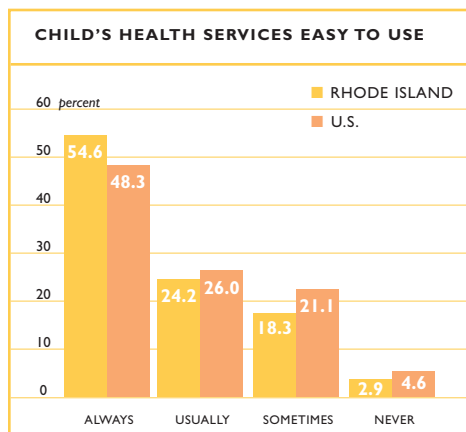
*2 The vocational rehabilitation program is a specialized program that assists in restoring the child's health.*



# Satisfaction with Health Care

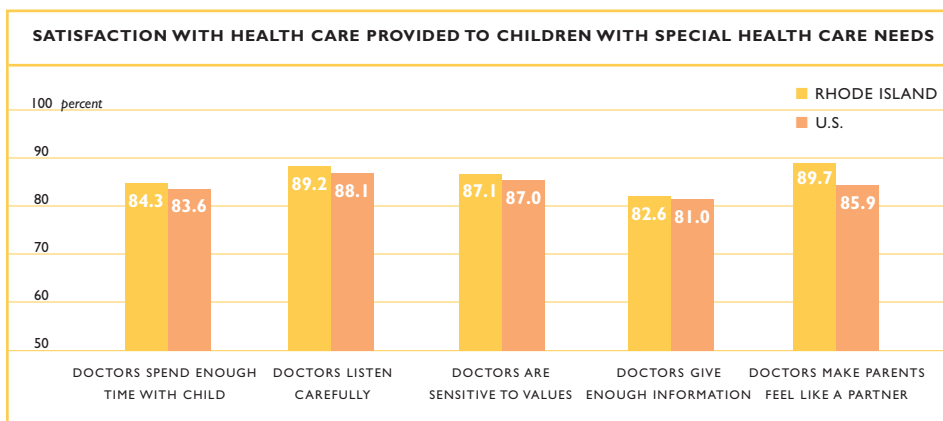
Overall, Rhode Island parents of children with special health care needs are more likely to be satisfied with their child's health services than those in the US. Furthermore, compared to the US, more Rhode Island parents believe that their child's health services are organized in a way that makes them easy to use. However, more than one in five Rhode Island parents of children with special health care needs say their child's health services are not easy to use.

- » 69.5% of Rhode Island parents of children with special health care needs are very satisfied with the health services their child receives, compared to 60.1% of parents in the US.
- » 5.4% of the Rhode Island parents of children with special health care needs are somewhat or very dissatisfied with their child's health services, compared to 8.4% nationally.
- » 54.6% of Rhode Island parents of children with special health care needs reported that their child's health services are organized in a way that makes them always easy to use, compared to 48.3% of parents in the US.
- » More than one in five parents of children with special health care needs in Rhode Island (21.2%) felt that their child's health services are organized in a way that makes them never or sometimes easy to use. This compares to more than one in four (25.7%) of their national counterparts.





Rhode Island parents of children with special health care needs are more likely than those in the nation to report a positive response in various measures of satisfaction with their child's health care.



Rhode Island parents of children with special health care needs say doctors always or usually:

- » spend enough time with the child (84.3% compared to 83.6% of parents in the US).
- » listen carefully to them (89.2% compared to 88.1% in the US).
- » are sensitive to their family's values and customs (87.1% compared to 87% in the US).
- » give them the specific information they needed (82.6% compared to 81% in the US).
- » make them feel like a partner in their child's care (89.7% compared to 85.9% in the US).



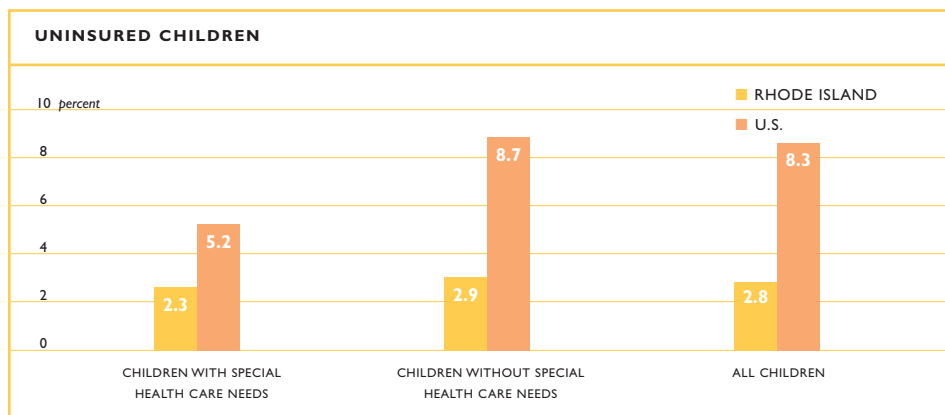
Rhode Island has one of the best health care coverage rates in the nation for all children, including children with special health care needs.



# Health Insurance

**Rhode Island has one of the best health care coverage rates in the nation for children. Over 97% of Rhode Island children (including those with special health care needs) are covered.**

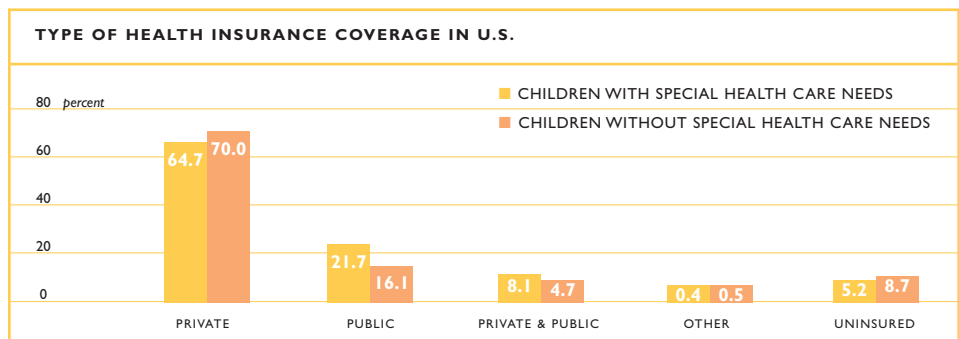
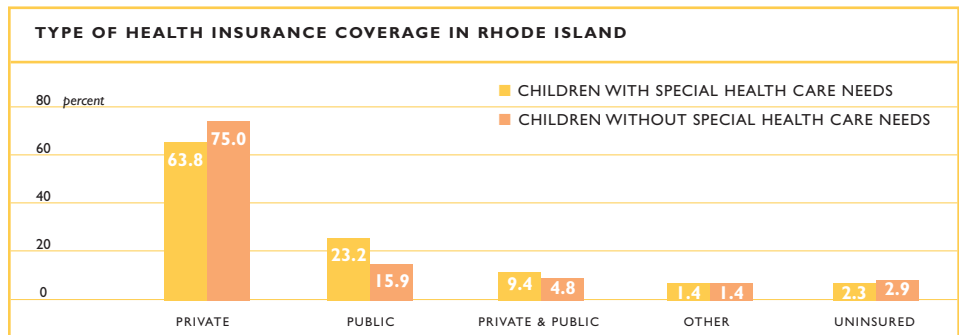
- » Children with special health care needs in the US were more than twice as likely as those in Rhode Island to have NO health care coverage at the time of the survey (5.2% vs. 2.3%).
- » Children without special health care needs in the US were three times more likely than those in Rhode Island to have NO health care coverage at the time of the survey (8.7% vs. 2.9%).
- » For all children under 18 years of age, US children were three times more likely than Rhode Island children to have NO health care coverage at the time of the survey (8.3% vs. 2.8%).





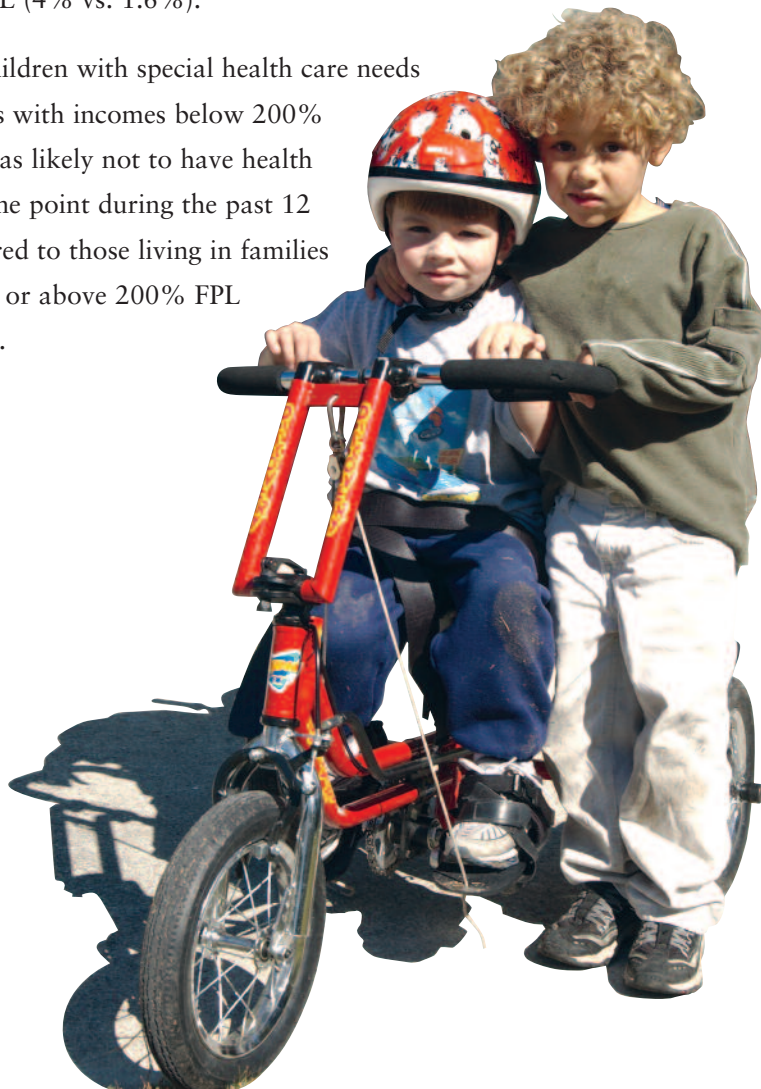
Children with special health care needs are more likely than children without special health care needs to have public insurance and are less likely to have private insurance, in both Rhode Island and the US. Children with special health care needs in Rhode Island are more likely than their national counterparts to have public health insurance.

- » In Rhode Island, children with special health care needs were less likely than children without special health care needs to have private insurance (63.8% vs. 75%) and were more likely to have public insurance (23.2% vs. 15.9%). The same pattern was seen in the US.
- » 32.6% of children with special health care needs in Rhode Island have either public insurance only or both private and public insurance, compared with 29.8% of their national counterparts.

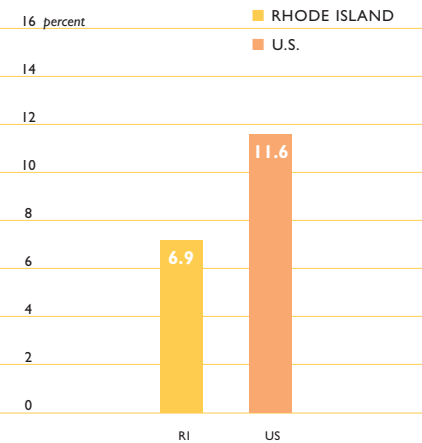


Although the uninsured rate for children with special health care needs in Rhode Island was lower than in the US, one in fourteen Rhode Island children did not have health insurance at some point during the past year. Rhode Island children living in low-income families were more likely to be uninsured both at the time of the survey and at some point during the previous 12 months.

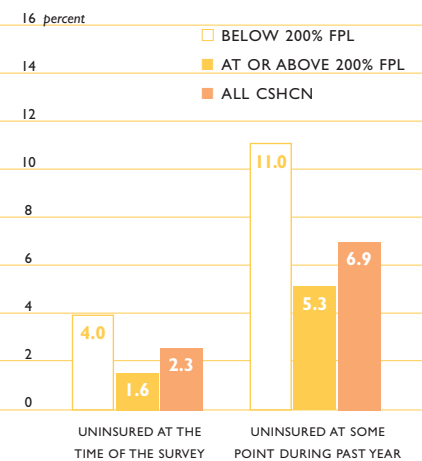
- » Even though only 2.3% of Rhode Island children with special health care needs had no health insurance at the time of the survey, 6.9% had no health care coverage at some point during the previous 12 months. Still, this rate is much lower than the US rate of 11.6%.
- » Rhode Island children with special health care needs living in families with incomes below 200% federal poverty level (FPL) were 2.5 times more likely not to have health insurance compared to those living in families with incomes at or above 200% FPL (4% vs. 1.6%).
- » Rhode Island children with special health care needs living in families with incomes below 200% FPL were twice as likely not to have health insurance at some point during the past 12 months, compared to those living in families with incomes at or above 200% FPL (11% vs. 5.3%).



**CHILDREN WITH SPECIAL HEALTH CARE NEEDS WHO WERE UNINSURED AT SOME POINT DURING THE PAST YEAR**



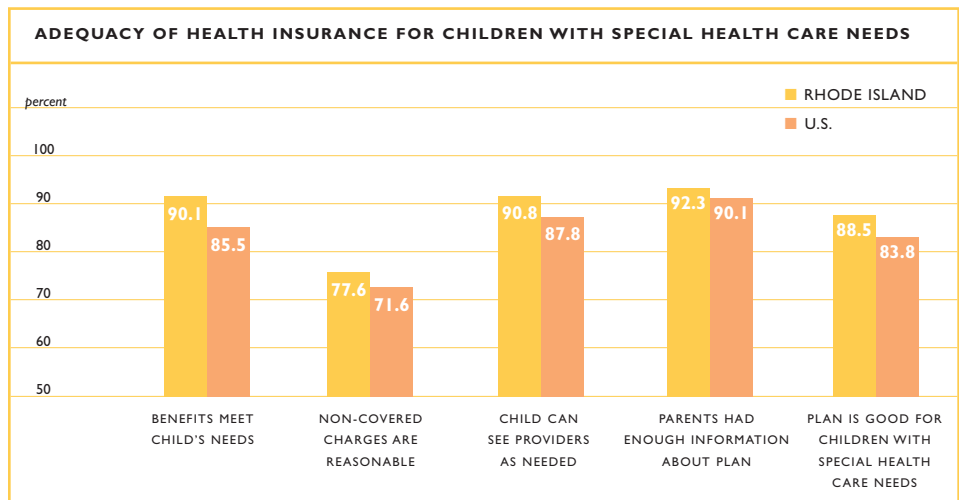
**UNINSURED CHILDREN WITH SPECIAL HEALTH CARE NEEDS BY FAMILY INCOME IN RHODE ISLAND**



**Compared to the US, more Rhode Island parents of children with special health care needs responded positively about their child's health insurance coverage and benefits and believed their child's health plan is good for their child.**

Rhode Island parents of children with special health care needs reported that:

- » their child's health insurance always or usually offers benefits or covers services that meet their child's needs (90.1% compared to 85.5% nationally).
- » the costs not covered by their child's health insurance are always or usually reasonable (77.6% compared to 71.6% of parents in the US).
- » their child's health insurance always or usually allows the child to see the health care providers they need (90.8% compared to 87.8% in the US).
- » they had enough information about how the child's health plan works (92.3% compared to 90.1% of parents in the US).
- » they believe the child's health plan is good for children with special health care needs (88.5% compared to 83.8% of US parents).







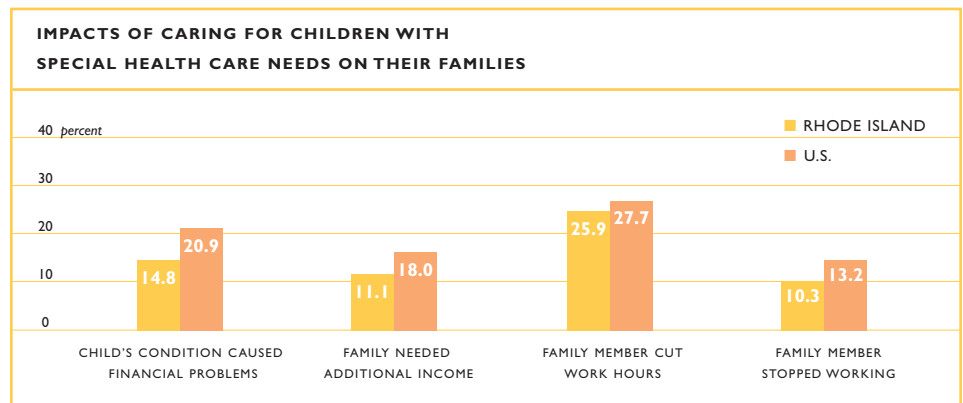
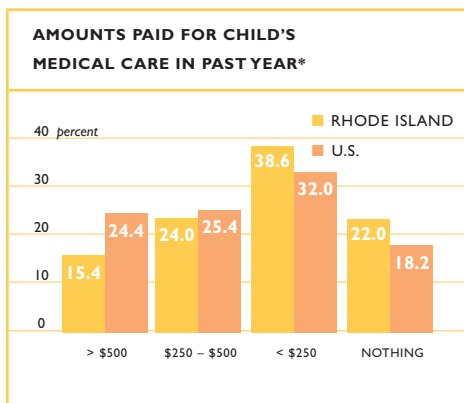
Compared to the US, more Rhode Island  
parents of children with special health  
care needs believe their child's health plan  
is good for their child.

# Impact on the Family

Rhode Island families with children with special health care needs have paid less for their child's medical care\* than their national counterparts. Additionally, fewer families in Rhode Island had financial or employment problems in caring for their child than families in the US. Still, more than one-third of Rhode Island parents have stopped working or cut work hours.

Rhode Island parents of children with special health care needs reported that:

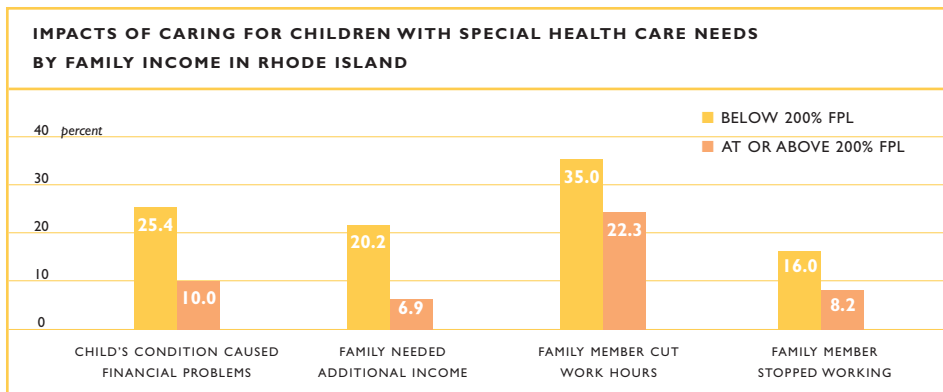
- » their family paid more than \$500 for their child's medical care\* during the past 12 months (15.4% compared to 24.4% of parents nationally).
- » their child's health conditions had caused financial problems for their family (14.8% compared to 20.9% of parents nationally).
- » they needed additional income to cover their child's medical expenses (11.1% compared to 18% of parents nationally).
- » their family members had cut down their work hours to care for their child (25.9% compared to 27.7% nationally).
- » their family members had stopped working because of the child's health conditions (10.3% compared to 13.2% nationally).



*\*Family medical care payments do not include health insurance premiums or costs that are reimbursed by insurance or another source. It does include out-of-pocket payments for all types of health-related needs such as medications, special foods, adaptive clothing, durable equipment, home modifications, and therapy.*



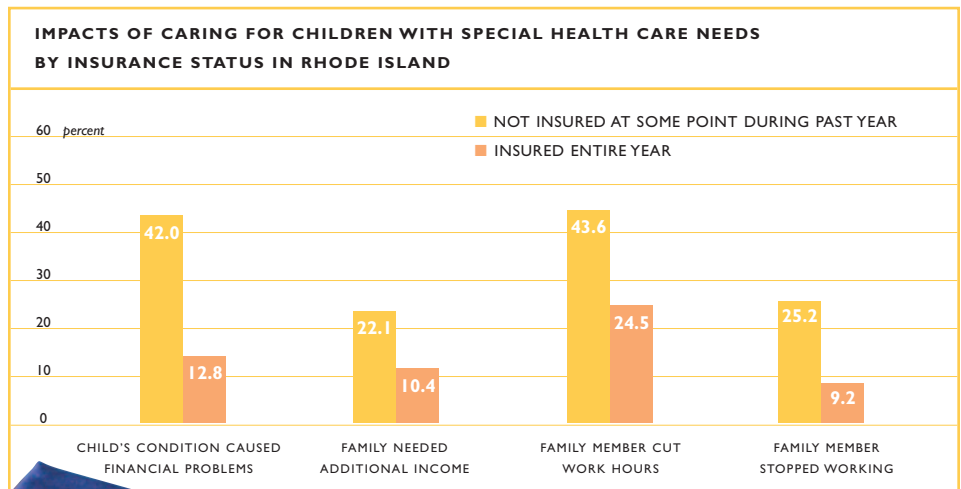
Rhode Island families of children with special health care needs with low incomes have more financial and employment problems in caring for their children than families with moderate or high incomes.



- » Rhode Island families of children with special health care needs with incomes below 200% FPL were 2.5 times more likely to have financial problems than families with incomes at or above 200% FPL (25.4% vs. 10%).
- » One in five (20.2%) Rhode Island families of children with special health care needs with incomes below 200% FPL needed additional income to cover their child's medical expenses, compared to 6.9% of families with incomes at or above 200% FPL.
- » Families of children with special health care needs with incomes below 200% FPL were more likely than families with incomes at or above 200% FPL to cut down on work hours to care for their child (35% vs. 22.3%).
- » Families of children with special health care needs with incomes below 200% FPL were two times more likely than families with incomes at or above 200% FPL to stop working because of their child's health conditions (16% vs 8.2%).

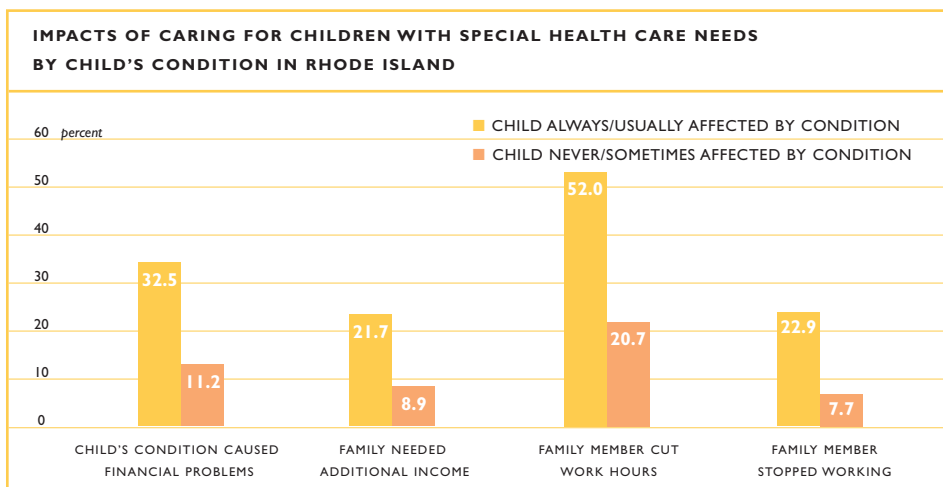


In Rhode Island, parents of children with special health care needs who were not insured at some point during the past 12 months were three times more likely to experience financial and employment problems in caring for their child than parents who were insured for the entire year (42% vs. 12.8%). They were also more likely to need additional income to cover the child's medical expenses, to cut down on work hours to care for their child, and to stop working because of their child's health.



Parents of children whose health conditions always or usually affected their child’s ability to do things other children their age do were three times more likely to experience financial problems than parents of children whose health conditions sometimes or never affected their ability (32.5% vs. 11.2%).

- » 21.7% of parents of children with special health care needs whose health conditions always or usually affected their child’s ability needed additional income to cover their child’s medical expenses. This compared to 8.9% of parents of children whose health conditions sometimes or never affected them.
- » More than one half of families with children whose health conditions always or usually affected their ability reported that a family member had cut down on work hours to care for the child. This compared to one in five families with children whose health condition sometimes or never affected their ability (52% vs. 20.7%).
- » More than one in five families with children whose health conditions always or usually affected their ability reported that a family member had stopped working due to their child’s health conditions. This compared to less than one in ten families with children whose health conditions sometimes or never affected their ability (22.9% vs 7.7%).



# Appendix

## » What is the National Survey of

### Children with Special Health Care Needs?

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The National Survey of Children with Special Health Care Needs (the survey) was conducted as part of the State and Local Area Integrated Telephone Survey (SLAITS), which is an ongoing surveillance system available at the state and local levels for tracking and monitoring the health and well-being of children and adults. The survey was funded by the Maternal and Child Health Bureau of the Health Resources and Service Administration, and conducted by the National Center for Health Statistics of the Centers for Disease Control and Prevention.

#### **The survey was designed to:**

- » Produce prevalence estimates of children with special health care needs using a standard set of screening questions,
- » Describe the type of services that these children need and use, and
- » Assess possible areas of improvement in their system of care.

#### **More specifically, the survey was designed to assess:**

- » The prevalence of special health care needs among children under 18 years of age in each state.
- » Whether special health care needs and the concerns of families are being addressed.
- » The quality of primary, specialty, and ancillary care that children receive.
- » Whether children with special health care needs receive comprehensive care in a medical home.
- » The factors associated with the receipt of better, more comprehensive care.
- » Whether families of children with special health care needs have adequate insurance to pay for the services their children need.
- » The impact of the child's health condition on the family.
- » Where children with special health care needs receive care coordination services.



- » How health insurance coverage for children with special health care needs compares with coverage for all children.
- » Why uninsured children from low-income households lack coverage, and whether their families are aware of Medicaid and the State Children's Health Insurance Program.

### » Screening for Special Health Care Needs

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Like other SLAITS modules, the National Survey of Children with Special Health Care Needs used the National Immunization Survey (NIS) sampling frame. The NIS is a large-scale random-digit-dial telephone survey that screens for the presence of young children in sampled households and collects information on children who fit the screening criteria. The National Survey of Children with Special Health Care Needs collected the required data at the state level from October 2000 to April 2002 in a manner that allows comparison across states and nationally.

The survey screening questions include five stem questions about general health care needs that could be the consequence of chronic health conditions. If a child currently experiences one of these consequences, follow-up questions determine whether this health care need is the result of a medical, behavioral, or other health condition, and whether the condition has lasted or is expected to last for 12 months or longer. Those with affirmative answers to the stem and both follow-up questions are considered to have a special health care need (Table 1).

**TABLE 1: SCREENING QUESTIONS USED IN THE NATIONAL SURVEY OF  
CHILDREN WITH SPECIAL HEALTH CARE NEEDS**

STEM QUESTION	FOLLOW-UP QUESTIONS
1 Does your child need or use more medical care, mental health, or educational services than is usual for most children of the same age?	(IF YES) Is your child's need for medical care, mental health, or educational services because of any medical, behavioral, or other health condition? (IF YES) Is this a condition that has lasted or is expected to last 12 months or longer?
2 Does your child currently need or use medicine prescribed by a doctor, other than vitamins?	(IF YES) Is your child's need for prescription medicine because of any medical, behavioral, or other health condition? (IF YES) Is this a condition that has lasted or is expected to last 12 months or longer?
3 Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do?	(IF YES) Is your child's limitation in abilities because of any medical, behavioral, or other health condition? (IF YES) Is this a condition that has lasted or is expected to last 12 months or longer?
4 Does your child need or get special therapy, such as physical, occupational, or speech therapy?	(IF YES) Is your child's need for special therapy because of any medical, behavioral, or other health condition? (IF YES) Is this a condition that has lasted or is expected to last 12 months or longer?
5 Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs treatment or counseling?	(IF YES) Has your child's emotional, developmental, or behavioral problem lasted or is it expected to last 12 months or longer?

NOTE: For households with more than one child, the phrase "does your child" was replaced with "do any of your children." Affirmative answers were followed by a question asking for the names or ages of the children with that particular health care consequence. The follow-up questions were then asked separately for each named child.

## » The Sample

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### Sample Size and Response Rate

The goal of the National Survey of Children with Special Health Care Needs sampling procedures was to generate samples representative of the state populations of children both with and without special health care needs. An additional goal of the survey was to obtain state-specific sample sizes that were sufficiently large to permit precise estimates of the characteristics of children with special health care needs in each state. To achieve these goals, state samples were designed to obtain 750 completed interviews with parents of children with special health care needs. A random-digit-dial sample of households with children less than 18 years of age was selected from each of the 50 states and DC.

Nationally, a total of 196,888 screening interviews with households having children were completed from October 2000 to April 2002. This resulted in 38,866 completed interviews with families of children with special health care needs, and 176,296 interviews completed for children without special needs during which questions about health insurance were asked. The weighted overall response rate for special needs interviews was 61 percent.

In Rhode Island, a total of 3,378 screening interviews with households having children were completed. This resulted in 750 completed special health care needs interviews and 3,058 interviews completed for children without special health care needs, during which questions about health insurance were asked. The weighted overall response rate for special-needs interviews was 62.3 percent.

### Selection of Sampled Children

All children under 18 years of age living or staying in selected households were screened for the presence of special health care needs. In households where a single child screened positive for a special health care need, that child was, by default, the child selected for the detailed special health care needs interview. If more than one child in the household screened positive, one such child was randomly selected for the detailed interview.

Children with a negative screen for special health care needs were eligible for the health insurance control sample interview. In households where a single child screened negative for a special health care need, that child was, by default, the child selected for the health insurance control sample interview. If more than one child in the household screened negative for special health care needs, one such child was randomly selected for the insurance interview. If a household had children with and without special needs, both interviews were administered in that household. Thus, in households with children under 18 years, there were three possible sampling outcomes:

- » One child selected for the special health care needs interview and no child selected for the health insurance control sample interview.
- » One child selected for the health insurance control sample interview and no child selected for the special health care needs interview.
- » One child selected for the special health care needs interview and one child selected for the health insurance control sample interview.

The survey respondent was the parent or guardian in the household who was most knowledgeable about the child's or children's health and health care. In the majority of households, the respondent was the child's mother or father (or female or male guardian).

### **Sampling Weights and Analysis**

Survey data were obtained through a complex sample design involving clustering of children within households and stratification of households within states. To produce estimates that are representative of children nationally and within each state, sampling weights must be used. These sampling weights were developed to account for the complex sample design of the survey and include adjustments for multiple-telephone households, unit non-response, and non-coverage of households with no telephone.

All results presented in this report have been weighted to reflect the population of children with special health care needs so the results from this survey could be generalized to Rhode Island's population of children with special health care needs. Data analyses are performed using SUDAAN software to take into account the complex sample design of the survey.

Unless otherwise specified, the respondents who did not know the answer or refused to provide the answer were excluded from the denominators when calculating the percentages. This exclusion of "don't know or refused" categories from denominators might slightly elevate the percentages in other categories.

### **References**

For more information about the National Survey of Children with Special Health Care Needs, go to [www.cdc.gov/nchs/data/series/sr\\_01/sr01\\_041.pdf](http://www.cdc.gov/nchs/data/series/sr_01/sr01_041.pdf).

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